

ORIGINAL ARTICLE

They “Don’t Know How to Deal with People Like Me”: Assessing Health Care Experiences of Gender Minorities in Indiana

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Abstract

Purpose: Within the LGBTQ+ community, the transgender and nonbinary (TGNB) population experience a disproportionate amount of discrimination when seeking health care. Such disparities may arise from lack of proper medical training and resources for providers or biases. In this study, we examine the health care experiences of TGNB individuals living in Southern Indiana.

Methods: We analyzed responses from TGNB respondents to an LGBTQ+ health care needs assessment survey in Southern Indiana. Respondents were asked about demographic data, their self-assessed health status, quality of health care received, whether they have a provider with whom they feel comfortable sharing their gender identity with, and if they have to commute to see their provider. Finally, respondents were asked an open-ended question about their health care experiences while living in Southern Indiana. Responses were coded and several themes emerged and were analyzed.

Results: Eighty-five TGNB individuals completed our survey. Less than half of respondents indicated that they had an LGBTQ+ -welcoming provider (44.7%). Individuals with an LGBTQ+ -welcoming provider were more likely to report their self-assessed health as excellent/good ($p=0.02$) and quality of health as excellent/very good ($p=0.03$) compared to individuals without an LGBTQ+ -welcoming provider. Five themes emerged from the write-in responses ($n=64$): discrimination (34.4%), invalidation (32.8%), distrust (28.1%), logistic concerns (35.9%), and positive experiences (35.9%).

Conclusion: The TGNB community living in Southern Indiana reports numerous barriers related to provider attitudes when obtaining health care. Additional training is needed to address provider biases and improve LGBTQ+ community health disparities.

Keywords: culturally competent health care; LGBT health disparities; LGBT health education; LGBT Indiana; LGBTQ; transgender health

Introduction

Members of the lesbian, gay, bisexual, and transgender (LGBT) community face discrimination in many aspects of their lives, including health care. This community also includes people who identify as queer, nonbinary, or fluid, and those who are questioning their identity. Throughout this article, therefore, we use the acronym LGBTQ+ to be inclusive of

the many identities encompassed under this umbrella. Compared to cisgender populations (i.e., individuals who identify as the gender they were assigned at birth), individuals in the transgender and nonbinary (TGNB) communities, which include individuals whose gender identity and/or expression does not match their sex assigned at birth, have unique health care needs related to gender-affirming

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treatment, including but not limited to access to hormone replacement therapy and gender-affirming surgeries.^{1,2} Too often, the TGNB community is met with providers who engage in “gatekeeping” behaviors like refusing to provide treatment or referrals, or requiring a burdensome number of steps for accessing care.^{3,4}

The breadth of research on TGNB communities continues to grow, including studies examining provider comfort in caring for TGNB populations, although results are mixed. Some studies show a promising trend toward inclusion and competent care and others with concerning trends toward growing disparities and inadequate care and microaggressions against the TGNB community, which includes misgendering or “deadnaming” (addressing someone by their birth name and not their chosen name).^{5–11} Often, providers express more comfort with lesbian, gay, and bisexual patients compared to TGNB patients and their unique needs.¹² Physicians and trainees often report little formal education in medical school and continuing medical education requirements that address TGNB-specific needs, and this lack of education contributes to their discomfort in providing care.^{13–16}

Research on the experiences of the TGNB community has shown lack of comfort in disclosures of identity with providers, and higher levels of discriminatory behaviors that lead to avoidance of health care.^{4,10,17,18} These issues are particularly salient for individuals whose gender identity falls outside of traditional male-female dichotomy, that is, nonbinary or genderqueer people.¹⁹ TGNB individuals have reported fear of discrimination as a factor for delaying needed health care, especially concerning their general and mental health needs, indicating a need for competent care.²⁰ A 2016 study found that nearly 30% of trans respondents reported postponing or not seeking needed medical care because of discrimination. Those who reported having to explain trans issues to their providers were four times more likely to postpone care.²¹

In this study, we present results from a survey conducted in Southern Indiana to determine the health care experiences and potential needs for the LGBTQ+ community in the area. We use a subset of the data to better understand the health care experiences of the TGNB community in Southern Indiana to develop targeted strategies to address this community's health needs and concerns.

Methods

Institutional Review Board approval

The Institutional Review Board at Indiana University approved the study for all age ranges. Individuals were informed of the research topic and provided consent/assent prior to beginning the survey.

Recruitment

Information regarding the study was shared with local LGBTQ+ organizations and businesses for distribution to their patrons. Information regarding the survey was also distributed on researchers' personal social media accounts (Instagram, Facebook, and Twitter). Finally, flyers containing QR codes were posted in public spaces.

Questionnaire

Our web-based survey, administered through Qualtrics, was open between September 30, 2020, and November 6, 2020. Gender identity was assessed by first asking respondents to indicate their gender identity (responses included man, woman, nonbinary [i.e., genderqueer or genderfluid], agender, unsure, or other) followed by asking if they identified as transgender (responses included yes, no, or unsure), and finally asking about their sex assigned at birth (responses included female, male, female but intersex, male but intersex, or unsure). The survey also included other demographic information, self-assessed health status, quality of health care received, whether or not the respondent had health insurance coverage, time since last health care visit, whether or not the respondent has a health care provider with whom they feel comfortable being open about their sexuality and/or gender, and, if they indicated that they do have an LGBTQ+ -welcoming provider, how far they commute to see them. Finally, respondents were asked an optional open-ended question: “What has been good and/or bad about your healthcare experiences while living in Southern Indiana?”

Respondents

Three hundred twelve LGBTQ+ individuals participated in the survey. Only respondents who did not identify as cisgender (i.e., they chose “yes” or “unsure” when asked if they identified as transgender) were included in this study ($n = 93$).

Statistical analyses

All data were analyzed using SPSS 27 (IBM Corp., Armonk, NY). We analyzed differences in item response

frequency, including demographic factors, insurance coverage, time since last health care visit, quality of health care received, self-assessed health status, whether the respondent indicated they had an LGBTQ+ -welcoming provider, and all five qualitative themes using a Pearson chi-square test. If chi-square assumptions were not met, Fisher's exact test (if the contingency table was 2×2) or likelihood ratio (if the contingency table larger than 2×2) was used. For all analyses, statistical significance was set at $\alpha = 0.05$ and corrected with Holm Bonferroni corrections. For significant findings, standardized residuals and column proportions of each contingency table were compared to better assess and discuss relationships between variables.

Qualitative analysis

We conducted qualitative coding using Dedoose (Socio-Cultural Research Consultants, Los Angeles, CA) using *in vivo* coding, a strategy of coding that recognizes and maintains participant language.^{22,23} Qualitative responses were read and coded by the first and second authors (Cohen's kappa = 0.79). Discrepancies were addressed and codes finalized in a coding conference. Five main themes emerged:

1. *Discrimination/fear of discrimination* included not only discrimination by physician/provider/staff/pharmacy and fear of discrimination but also experiences of exclusion in health care settings (i.e., cisgender, heteronormative assumptions in provider questions, exclusive intake forms, and exclusive spaces), and developing harm-reduction strategies to minimize anticipated stigmatization (i.e., not disclosing sexual orientation or gender identity for fear of receiving stigma/discrimination and avoiding care due to fear of stigma/discrimination).
2. *Invalidation* included experiences of "gatekeeping" in health care (i.e., for sexually transmitted infection screening, hormone therapy, and gender affirmation surgery), gender or sexual orientation invalidation (i.e., being misgendered by provider and/or staff despite corrections), and health complaint invalidation.
3. *Distrust of health care providers* included a skepticism regarding which providers are LGBTQ+ -welcoming, lack of LGBTQ+ -welcoming providers, providers demonstrating LGBTQ+ incompetence, and having to teach their provider about LGBTQ+ health issues.

4. *Logistic concerns* included long wait times, no primary care provider, commuting for care, cost of care, insurance issues, providers not accepting new patients, and transportation
5. *Positive experiences*, which included favorable experiences in health care settings.

All write-in responses to this question included at least one of these themes.

Results

Quantitative analyses

Demographics. A total of 93 respondents identified as either trans or were unsure of their gender identity. Of those, 85 completed the survey (91.4% completion rate). Only those who completed the survey were included in any analysis. Only individuals 14 years of age and older were included in analysis, which eliminated one 8-year-old participant. The average age of respondents was 28.4 ± 11.0 years, ranging from 14 to 65. The vast majority identified as white (87.1%), while the remainder identified as mixed/other. Gender identities were as follows: nonbinary (56.5%), women (17.6%), men (16.5%), or other (9.4%). Sexual orientation varied: 37.6% identified as queer, 29.4% were bisexual or pansexual, 18.8% were gay or lesbian, 5.9% were asexual, and 8.2% identified as other, unsure, or heterosexual (Table 1).

Overall health status. Data regarding overall health status of respondents are reported in Table 2. Less

Table 1. Demographic Information

	N	%
Age		
14–17	5	5.9
18–25	40	47.1
26–35	27	31.8
36–45	4	4.7
45+	9	10.6
Gender identity		
Nonbinary	48	56.5
Woman	15	17.6
Man	14	16.5
Other	8	9.4
Sexual orientation		
Queer	32	37.6
Bisexual or pansexual	25	29.4
Lesbian or gay	16	18.8
Asexual	5	5.9
Other/unsure/heterosexual	7	8.2
Race/ethnicity		
White	74	87.1
Other/mixed	11	12.9

Table 2. Quantitative Data

	N	%
Health insurance coverage		
Yes	77	90.6
No	5	5.9
Unsure	3	3.5
Time since last visit with health care provider		
<6 months	50	58.8
6 months–1 year	23	27.1
1–2 years	6	7.1
2–5 years	4	4.7
5+ years	2	2.4
Quality of health care in Southern Indiana		
Excellent/good	37	43.5
Fair/poor	41	48.2
Have not received	7	8.2
LGBT+-welcoming provider		
Yes	38	44.7
No	23	27.1
Unsure	24	28.2
Commute to see LGBT+-welcoming provider		
No commute	24	63.2
0–1 h	10	26.3
2–3 h	4	10.5
Self-reported health status		
Excellent/very good	25	29.4
Good	34	40.0
Fair/poor	26	30.6

than half of respondents indicated that they had an LGBTQ+-welcoming provider (44.7%). Of individuals who reported having an LGBTQ+-welcoming provider, 26.3% commute 0–1 h to see that provider, and 10.5% commute 2–3 h. When asked about their self-assessed health status, 29.4% rated their health as excellent/very good, 40.0% as good, and 30.6% as fair/poor. Respondents were also asked about the quality of health care they have received: 43.5% rated their care as excellent/good and 48.2% as fair/poor, while 8.2% indicated that they have not received care in Southern Indiana. Individuals who had not received health care in Southern Indiana were not asked about quality of their care ($n=7$). Most participants reported that they had seen a health care provider within the last 6 months (58.8%), while 27.1% reported their last visit was between 6 months and 1 year prior, 7.1% between 1 and 2 years prior, and 7.1% reported there had been 2+ years since they had last seen a health care provider.

Trans women were more likely to report having an LGBTQ+-welcoming provider, while nonbinary individuals were less likely to report having such a provider ($p=0.02$). Furthermore, individuals with an LGBTQ+-welcoming provider were more likely to report their self-assessed health as excellent/good ($p=0.02$) and

quality of health as excellent/very good ($p=0.03$) compared to individuals without an LGBTQ+-welcoming provider.

Qualitative theme analyses

Of the 85 TGNB people who completed the survey, 64 answered the optional free-response question (75.3%). Only those who answered the free-response question were included in theme analyses. We found no difference in demographic factors between those who chose to answer the open-ended question and those who did not. Frequencies of themes can be found in Table 3.

Discrimination. Of 64 individuals, 34.4% reported discrimination or fear of discrimination. Illustrative examples of responses coded as discrimination include the following:

I've also experienced extensive discrimination from medical providers in the past. I even had months when I couldn't get my prescription filled because of harassment and discrimination from [local] pharmacy employees and pharmacists (trans man, 25).

... I am always deadnamed and misgendered while accessing healthcare. I sometimes worry about correcting this and experiencing discrimination (nonbinary, 22).

Trans men reported more discrimination or fear of discrimination than nonbinary individuals ($p<0.01$). Individuals with an LGBTQ+-welcoming provider did not experience significantly less discrimination compared to those without an LGBTQ+-welcoming provider. Finally, we found no significant interaction between experiencing discrimination in health care and quality of care received, self-assessed health status, or time since last visit.

Invalidation. Invalidation was reported by 32.8% of respondents. Illustrative examples include the following:

*In the past, even doctors who have supposedly been made aware of my gender identity *still* do not make any effort to respect it, and they have repeatedly misgendered me to my face in spite of this (nonbinary, 30).*

Table 3. Theme Frequency

	N	%
Completed open-ended question	64	75.3
Theme		
Discrimination or fear of discrimination	22	34.4
Invalidation	21	32.8
Distrust	18	28.1
Logistics	23	35.9
Positive experiences	23	35.9

I've had doctors argue with me about my sexual orientation and make claims that all transgender people are straight (nonbinary, 31).

There were no significant differences between those coded for invalidation and those coded for invalidation based on demographic factors, whether they had an LGBTQ+-welcoming provider, quality of health care, self-assessed health status, or time since last visit.

Distrust. Distrust in health care and/or providers was reported by 28.1% of respondents. Examples of those coded for distrust include the following:

...I do not have a [general practitioner], partially because I do not know how general practitioners in this area would receive trans patients (trans man, 24).

I do know there are a couple of LGBTQ+ doctors, and most of the doctors I've met have been cool with the L, G, and B identities, but apparently not with transgender individuals (nonbinary, 22).

Also, finding a therapist has been traumatic with one person telling me that they "don't know how to deal with people like me," referring to my non-binary identity (nonbinary, 33).

Individuals who expressed distrust were more likely to report the quality of care they have received in Southern Indiana as fair/poor (vs. good/excellent) compared to those who did not express distrust ($p=0.03$). Time since last visit with a provider ($p=0.65$) nor self-assessed health status ($p=0.08$) was associated with reports of distrust.

Logistics. Logistic concerns to seeing a provider were reported by 35.9% of respondents. Examples include the following:

My [hormone therapy] has always been prescribed out of [a larger city], because there seem to be no practitioners out here in the hinterlands that are willing to manage cases such as mine (trans man, 28).

I've also had issues with being uninsured for months at a time due to job transitions and Medicaid difficulties (trans man, 25).

We found no significant relationship between experiences of logistic barriers to health care and any other variable assessed in this study.

Positive experiences. Positive experiences in health care were reported by 35.9% of respondents. Examples of positive experiences include the following:

Both my doctor and my therapist are very accepting of my LGBT identities and are willing to keep it private (as opposed to disclosing the information to my parents) (nonbinary, 15). The only positive healthcare experiences I've had have been with providers who also identify as queer or trans (nonbinary, 28).

Individuals 14–17 years of age were more likely to report positive experiences than other age groups, while those 18–25 years of age were less likely to report positive experiences than other age groups ($p=0.001$). Individuals with an LGBTQ+-welcoming provider reported significantly more positive experiences in health care compared to those without an LGBTQ+-welcoming provider ($p=0.04$). In addition, individuals who reported positive experiences were more likely to rate the quality of care they have received as good/excellent compared to individuals who did not report positive experiences ($p=0.001$). We found no association between positive experiences and self-assessed health status ($p=0.78$) nor time since last visit with a health care provider ($p=0.93$).

Themes interacting. Finally, we examined relationships between themes. We observed significant associations between reporting positive experiences and discriminatory experiences, where individuals were less likely to report discrimination experiences if they had reported positive experiences ($p=0.03$). Furthermore, we found a significant association between discrimination and logistics, where individuals who discussed logistic concerns in their health care experiences were less likely to report experiencing discrimination ($p<0.01$). We also found that individuals who expressed distrust in the health care system or their provider reported fewer positive experiences ($p=0.04$).

Discussion

Most respondents (85.9%) reported receiving care in the last year, indicating that the majority of the TGNB community is accessing health care. However, fewer than half (44.7%) reported having an LGBTQ+-welcoming provider. Of those who reported having an LGBTQ+-welcoming provider, over one-third reported commuting up to 2 h to receive care from that provider. Our findings demonstrate that individuals often cannot find competent providers locally and are forced to commute long distances to see such providers. The TGNB community is also more likely to live in poverty or be unemployed, which may prevent them from being able to travel to access culturally competent care.²⁴

Many respondents (56.5%) identified as nonbinary, which represents an understudied population within the TGNB community. Compared to trans women,

nonbinary individuals were significantly less likely to report having an LGBTQ+-welcoming provider ($p=0.01$). While studies focused on nonbinary populations are sparse, recent studies suggest that nonbinary and genderqueer individuals have unique health care needs compared to trans women and trans men. For example, nonbinary individuals often feel misunderstood, disrespected, and frustrated by providers who approach them from a binary trans perspective.²⁵ Furthermore, genderqueer or nonbinary individuals are less likely than trans individuals to have a doctor who knew about their gender identity and are also less likely to be treated with respect by their provider.²⁶ That this population comprised over 50% of the trans community who responded to our survey demonstrates the need for more culturally competent care for individuals throughout the gender spectrum.

A lack of knowledge about and exposure to nonbinary individuals throughout medical training likely contributes to the poor care this population has received. A median of 5 h throughout the 4-year medical school curricula is dedicated to LGBTQ+-related content. Of these hours, it is unclear how much of this time was TGNB related or if any was focused on the nonbinary populations specifically.²⁷ When physicians do not learn about their patient population in training, they often report relying on that population of patients to educate them. This presents a source of contention, as TGNB patients report they should not have to educate their providers about themselves.²⁶ When not properly trained, physicians may dead-name, misgender, or otherwise conduct themselves in a way that would make TGNB individuals less likely to report them as welcoming.

In contrast to prior studies, we found that trans men were more likely to report discrimination than nonbinary individuals.¹⁹ Interestingly, discrimination was not associated with whether the respondent had an LGBTQ+-welcoming provider. This could indicate that providers who report LGBTQ+-welcoming practices may be more adequately trained regarding lesbian, gay, and bisexual health needs, but fall short when addressing trans patient and their health needs. This finding may also indicate additional sources of discrimination beyond the physician, as when respondents reported discrimination from ancillary staff and other health care workers.²⁸

One-third (32.8%) of respondents reported episodes of invalidation in their health care. Invalidation could be personal, as when the provider does not re-

spect the patient nor their identity, or systematic, including the inability to update electronic medical records (EMR) with appropriate pronouns or preferred names, leading providers to use incorrect names or pronouns, especially when faced with large clinic capacities and diminishing patient-provider interaction times.²⁹ Sweeping systems-based changes to EMR and health policy may be indicated to ensure documents can be updated before the patient-provider interaction.

Respondents also reported experiences in which their provider demonstrated a complete lack of understanding of what sexual orientation and gender identity mean. Lack of provider understanding places an additional burden of explanation on the patient. This emphasizes the importance of LGBTQ+-inclusive medical education throughout medical school and in continuing medical education. In contrast to previous studies, we found no association between individuals who expressed distrust and time since last visit with provider.²³ Respondents who expressed distrust did, however, report lower quality of care.

Respondents reported many of the same logistical barriers to accessing medical care as the general population, including long wait times to access care, the need to commute to access care, and insurance issues.^{30,31} In this community, logistic concerns compound other barriers, including fearing discrimination and invalidation from providers, thus making accessing care more difficult. We found that individuals who reported logistical concerns were significantly less likely to report discrimination, suggesting that individuals are willing to travel for care to avoid discrimination from their providers. If more providers were available and welcoming, patients may no longer need to travel for competent care.

Over one third of respondents (35.9%) reported a positive experience while accessing health care. Unsurprisingly, individuals with an LGBTQ+-welcoming provider reported significantly more positive experiences and a higher quality of care compared to those without an LGBTQ+-welcoming provider. Interestingly, several respondents indicated that their health care experience was positive because their provider identified as LGBTQ+. Unfortunately, LGBTQ+ students often do not disclose their sexual orientation or gender identity status while in medical school, nor do medical schools consider those who are LGBTQ+ to be underrepresented minorities.³¹ Based on our findings, medical institutions should develop or expand

efforts to create safe environments for LGBTQ+ patients and students, including additional training in LGBTQ+ health and cultural competency. Our finding emphasizes that having appropriate, competent care with a trustworthy provider improves health care experiences and likely increases willingness to use health care services. In turn, this could greatly benefit patients' wellbeing and health status.

Future studies should continue to explore the unique needs and challenges faced by TGNB members of the LGBTQ+ community. Since our population was geographically limited, other studies should assess health care provider attitudes in other regions. Furthermore, additional studies should delineate experiences with different types of health care providers, including those who provide mental health care versus medical or surgical health care.

Conclusion

This study helps illustrate the relationship between provider attitudes and health care access for TGNB patients. While the TGNB community in Southern Indiana navigate general barriers in the United States' health care infrastructure, including costs and commutes, they must also navigate the complexities of finding a provider who respects and affirms their identity. To address the health disparities of these populations, efforts should be made by medical institutions to educate current and future providers, as well as ancillary staff, on the broad spectrum of gender identity and related health topics.

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Abbreviations Used

EMR = electronic medical records
TGNB = transgender and nonbinary